

**Strategies for Informed Consumer Choice of**  
**Health Care Quality Data: Describing Target Audiences for**  
**Facility-Specific Quality Information Provided by Medicare—**  
**Final Report**

**Purpose:** On behalf of the Centers for Medicare and Medicaid Services (CMS), a project team conducted a selective review of research as well as 12 focus groups (in 3 cities) consisting of general consumers of Medicare information, Medicare beneficiaries and caregivers, and formal intermediaries who assist beneficiaries and caregivers with nursing home placement decisions. The overall purpose of this project was to describe the primary and secondary target audiences for the public release of facility-specific quality information provided by CMS, focusing on audiences for data related to nursing homes and home health agencies and on those target audiences who might have an incentive to use quality information for advance planning (e.g., selection and placement decisions). More specifically, the objectives of this project was to determine the following:

- 1) What are the characteristics of people who are “early adopters” or advance planners (i.e., caregivers and/or Medicare beneficiaries who take proactive steps at getting information about the availability and quality of nursing homes and home health care agencies), and how do they compare to other segments of the target audiences?
- 2) Are there related consumer behaviors that might predict a person’s receptivity to quality information?
- 3) What triggers a person’s decision to act and/or to seek out information?
- 4) Where do caregivers turn for information when they decide to act?
- 5) How receptive are they to information about quality?
- 6) What are the strategic implications of these characteristics and behaviors to communication campaigns and messages?

**Results from Selective Research Review:** Key findings from a review of 26 research reports and studies salient to this study are summarized below:

I. The Challenge of Older Consumers

- The present cohort of older Americans has limited awareness of variations in health care quality.

- Most people judge quality based on the individual characteristics of their caregivers, rather than objective measures of clinical quality.
- Most older consumers and their caregivers respond to crises, instead of planning ahead for dependent care.
- Most older Americans tend to defer to the judgment of clinicians, rather than seek out information to make their own independent health care decisions.
- Older Americans depend on family and friends as guardians, caregivers, sources of information, and surrogate decision-makers.

## II. Family and Other Caregivers

- The most common informal caregiving relationship is that of the adult child of elderly parents, followed by spouses and other relatives.
- Demographic characteristics of caregivers generally mirror those of the general population.
- Caregiving covers a spectrum of activities, but consumers often equate the term with personal hands-on care.
- Most caregivers balance work and family life, in addition to caring for elders.
- Many caregivers find it difficult to obtain needed services, both for financial reasons and because of the “hassle factor” associated with finding out what they need to know.
- Most caregivers know how to arrange for nursing home care, but few understand about the scope of services that encompass home health care.

## III. Barriers to Change

- Most elders and their caregivers are reluctant to anticipate, much less plan for, future dependency or long-term care needs, even in the face of apparent disability or functional decline.
- Many individuals feel ill prepared for the placement decisions, even though they have long known that the need for such a placement is looming on the immediate horizon.

- Older people and their family caregivers are generally unfamiliar with the range of available services for dependent elders, except for nursing home care.

#### IV. Trajectories of Decline and Triggers to Actions

- Family caregivers may fail to plan ahead because they become accustomed to intermittent crises and assume that their loved one will continue to bounce back.
- Hospitalization following acute episodes of illness may provide opportunities for health care providers to intervene in the lives of elderly patients at earlier stages to maintain as much independence as possible and slow the process of decline.

#### V. Characteristics of Advance Planners

- Research on behaviors around facility placement provides little insight into the behaviors and motivations of those potential “early adopters” of quality information who *do* plan ahead.

#### VI. Understanding and Using Quality Measures

- Consumers find it difficult to relate to quality measures as indicators of how well a facility performs in providing care.
- Most people have little or no experience with nursing homes, home health agencies and other health care providers and have trouble understanding what it means to make choices among these health care providers.
- Health care professionals express concerns about the potentially deleterious effects of public reporting of quality information.

**Results from Focus Groups:** Key findings from the 12 focus groups are summarized below:

##### I. Characteristics and Behaviors of Advance Planners and Likely “Early Adopters” of Quality Information

- Those most actively engaged in advance planning for needs relating to aging are men and women upon whom the responsibility for caregiving has fallen in the past.
- Advance planners in this category have first-hand experience trying to gather information on long-term care alternatives and understand the value of good information.

- Advance planning for needs related to long-term care and/or aging does not reflect a consumerist orientation, in general.
  - Advance planners were motivated by experience, not by consumerism.
  - Respondents emphasized the difference between planning for long-term care and other major purchasing decisions: “Choosing a nursing home is not like choosing to buy a car.”
- Male heads-of-household accustomed to assuming the fiduciary responsibilities of the family may represent a distinct category of individuals motivated to plan ahead for needs relating to aging, regardless of prior caregiving experience.
  - In contrast to advance planners with prior caregiving experience, these individuals appeared to keep their emotional distance from the planning process, even when they had aging relatives for whom they were responsible.
  - Notwithstanding their emotional distance and even denial, these individuals appeared to be receptive to factual information and to offers of help that allow them to engage in information-gathering in a detached and systematic way.
- Men may assume the role of planners and information-gatherers in the family, while women may assume the role of caregivers.
  - Several respondents suggested that there is often a kind of division of labor in families, such that women deal with the physical care and emotional issues and men gather information (which allows them to maintain their emotional distance).

— However, the limitations of this research study did not permit exploring this issue in depth.
- Advance planning for funerals is common, but it is not associated with advance planning for health care or other needs related to aging.
  - Death is recognized as inevitable, but the declining health and dependency that precede death are not topics most people care to think about.
- Only children, especially those who are single, may also recognize the need to plan ahead, but they often do not know what to expect or where to turn for help.

- Most only children, nevertheless, thought that having information available early on would be useful.

## II. Triggers to Action

- Witnessing problems relating to aging and functional decline in other people's relatives can prompt concern about one's own aging relative or loved one.
- Experienced caregivers and information intermediaries recognize triggers of concern further "upstream" in the trajectory of functional decline.
  - Respondents who were experienced caregivers as well as hospital discharge planners were more likely than others to recognize relatively subtle signs and signals that occurred long before there were serious signs of decline.
- Most caregivers who lack prior experience delay taking action until there are more obvious signs of decline, further "downstream" in the process.

## III. Perceived Informational Needs and Concerns about Quality

- Most caregivers express the need, first, for information about available services and covered benefits.
  - Concerns about quality arise once they have a clearer understanding of available alternatives.
- Most caregivers are interested in information relating to quality of care in nursing homes.
  - Concerns about the quality of care in nursing homes, fueled more often by sensational cases in the media rather than personal experience, often reinforce caregivers' natural resistance to considering nursing home placement for their parents or spouses.
  - Yet those concerns have the effect of raising caregivers' awareness and may be a motivating factor about the importance of quality, creating an opportunity for communicating about variations in quality.
- Caregivers' concerns about home health care services relate more to discomfort with "strangers in the house" than to concerns about quality.
  - Surprisingly, this aversion to care in the home was sometimes stronger than the caregivers' aversion to assisted living or institutional long-term care.

- Caregivers and intermediaries express interest in comparative facility-specific information about quality, but they are most likely to use it in conjunction with other, more subjective, sources of information (e.g., seeking recommendations from family and friends, touring various nursing homes).
- Although hospital social workers and discharge planners are important sources of information to family caregivers, caregivers who are most actively engaged in advance planning activities for their family members seek information from many, varied, and disparate sources.
  - No single source of information emerged from these experiences as most important or primary.

#### IV. Implications for Communication Strategies: Messages and Channels

- Target “early adopters” and advance planners as the primary caregiver audience.
- Frame messages to tap into the personal characteristics and motivations of target audiences.
  - Experienced caregivers appear to understand, from past experience, how difficult it is to emotionally deal with a loved one’s functional decline and loss of independence.
  - They may therefore be responsive to messages that acknowledge and tap into this emotional “realism.”
  - On the other hand, male heads-of-household, who may not be emotionally prepared to deal with a loved one’s functional decline, may consequently resist messages based on emotional appeal, but respond to those that appeal to their rational side and their sense of paternalism.
- Target “contemplators,” such as only children or sole caregivers, as secondary caregiver audience.
- Frame messages to move “contemplators” to action by honing in on triggers, while acknowledging their emotional resistance.
  - The challenge in motivating contemplators to take action lies in getting them to recognize potential needs before they reach the crisis stage, and to recognize that planning ahead for such needs does not constitute a betrayal of their loved ones.

- Target hospital social workers, physicians and discharge planners as a primary intermediary audience.
- Frame messages to encourage intermediaries to engage in anticipatory guidance with family caregivers, focusing on “upstream” issues.
- Disseminate information through a variety of channels in the local community, to reach family caregivers and raise their awareness before they are in crisis.
  - Doctors’ offices, emergency rooms waiting rooms, and pharmacies were mentioned most often by respondents, along with libraries, post offices, and other community locations.
- Acknowledge and build on concerns about the care provided in nursing homes to promote interest in quality.
- Frame messages around quality information within the context of larger issues related to planning.
  - Facility-specific quality information provided by Medicare cannot help consumers make meaningful decisions by itself.
  - It should be promoted as part of a larger set of information about costs, benefits, and quality of services for the elderly, including those that are not covered by Medicare.